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NORTH WEST
CONGENITAL HEART DISEASE NETWORK

North West
Congenital Heart Disease
Operational Delivery Network

Annual Report
2021

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Document Approval	Gordon Gladman	
Document Abstract	This annual report for the North West CHD Network outlines the background to the network, its vision and key objectives, achievements and challenges, and key updates for the period February 2021-January 2022. It also looks to the future, providing an overview of plans from February 2022.	

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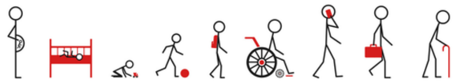
13/06/22	V4	Gordon Gladman	Editorial	



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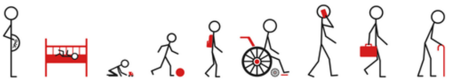


- **Foreword from Chair**

Chair Network Board
Dr Nayyar Naqvi OBE

It has been my privilege to continue as Chairman of the Board of the Congenital Heart Disease Network of the North-West, North Wales and the Isle of Man. We have been functioning for just over two years. The Board is made up of a dedicated team of members who are highly knowledgeable in the field of congenital heart disease and paediatric cardiology. All members are making a significant contribution to the management of patients of all ages with congenital heart disease.

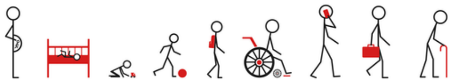
We have faced the challenges imposed by the COVID epidemic for the past two years and done our best to overcome these. Data collection across the Network is progressing well. Work is continuing on establishing the Network Data Base and Single ACHD Patient Treatment List. At each meeting updates are received from the different parts of the Paediatric Partnership Network, reviewed and discussed. The Network's Governance structures have improved immensely from the initial national peer review allowing the Network to be more influential in its decision making.

The Network's transformation from informal clinical network to a formal operational delivery network has been recognised. The feedback received nationally and from the Commissioners is that the Network has grown in confidence and is playing a significant role in fulfilling its responsibilities. The Lead Nurse has successfully championed a number of Network projects. I am grateful for the contribution made by the patient representatives on the Board. PPV (Patient Public Voice) group is a comprehensive group of representatives that has a lot to offer and it is our intention to ensure this group continues to prosper. We remain firm in our resolve to provide our patients across the Network the highest quality of care.

Nayyar

No man is an island entire of itself;
every man is a piece of the continent, a part of the main;
any man's death diminishes me,
because I am involved in mankind.
And therefore never send to know for whom
the bell tolls; it tolls for thee.

Extract from 'No Man is an Island' by John Donne



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- **Clinical Director's Network Year Review**

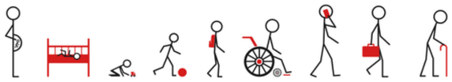
Network Clinical Director
Dr Gordon Gladman
Consultant Paediatric Cardiologist

With the persisting challenges created by the ongoing COVID 19 pandemic, 2021 has been a testing but none the less, productive year for the Network.

Our ‘core team’ have worked hard to maintain communication with network members, monitor the clinical effect of the pandemic on the provision of care across the region and provide support wherever possible. I would like to take this opportunity to specifically mention certain individuals for their role in the network. We have witnessed the retirement of Denise Szpunar, one of our original ‘job-sharing’ managers and I thank her for the significant part she played in establishing the Network. I would also like to thank Helen Sanderson (the other ‘job sharing’ manager) for stepping up to cover the void left by Denise’s departure. The commitment and enthusiasm that our Lead Nurse (Linda Griffiths) has brought to the Network cannot be emphasised too strongly. The core management team has witnessed ‘ups and downs’ throughout the year, with both serious illness and happier pregnancy news being conveyed by colleagues. Whether recovering from illness or leaving to start maternity leave, I wish my ‘friends and co-workers’ well and look forward to hopefully welcoming them back to the team in the future. In the interim, I can only thank the other ‘2020 network recruits’ for covering (wherever possible) the inevitable gaps that were created.

The annual report provides an opportunity to ‘showcase’ the achievements of network members (clinical, administrative and PPV) in maintaining a clinical service in the face of significant adversity (be it coronavirus or a series of unexpected illnesses that impacted on the ACHD Consultant team!!). There is no denying that the pandemic has created unique problems regarding the provision of care, with ‘routine’ patient reviews proving impossible if ‘covid-19 safety precautions’ were to be observed. However, patients were ‘triaged’ for clinical need on a regular basis and subsequently assessed as felt appropriate, with network members providing additional care opportunities wherever possible. Happily, the network has not identified evidence that those in need of clinical care came to significant harm as a result of the specific 2020/21 challenges. Clinical providers of care are to be congratulated for maintaining ‘steady state’ surgical and cardiac catheter waiting lists, with the data beginning to now demonstrate a decline in the number of patients ‘significantly overdue’ their routine outpatient reviews. Although hopefully the effects of covid-19 are now in decline, with a finite number of providers, ‘catching up’ is likely to take several years. I feel confident that the willingness of clinical members to ‘continue to step up’ to the on-going challenges and by maintaining the close co-operation that exists with our PPV group and the patients they represent, a safe and sustainable service can be maintained.

I thank all those network members involved in providing, monitoring and supporting the care for those born with congenital heart disease. I believe the network will continue to play an important role in maintaining standards and over-seeing the delivery of both paediatric cardiology and ACHD care throughout the region, whether in a hospital setting or the wider community.



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ABOUT THE NETWORK

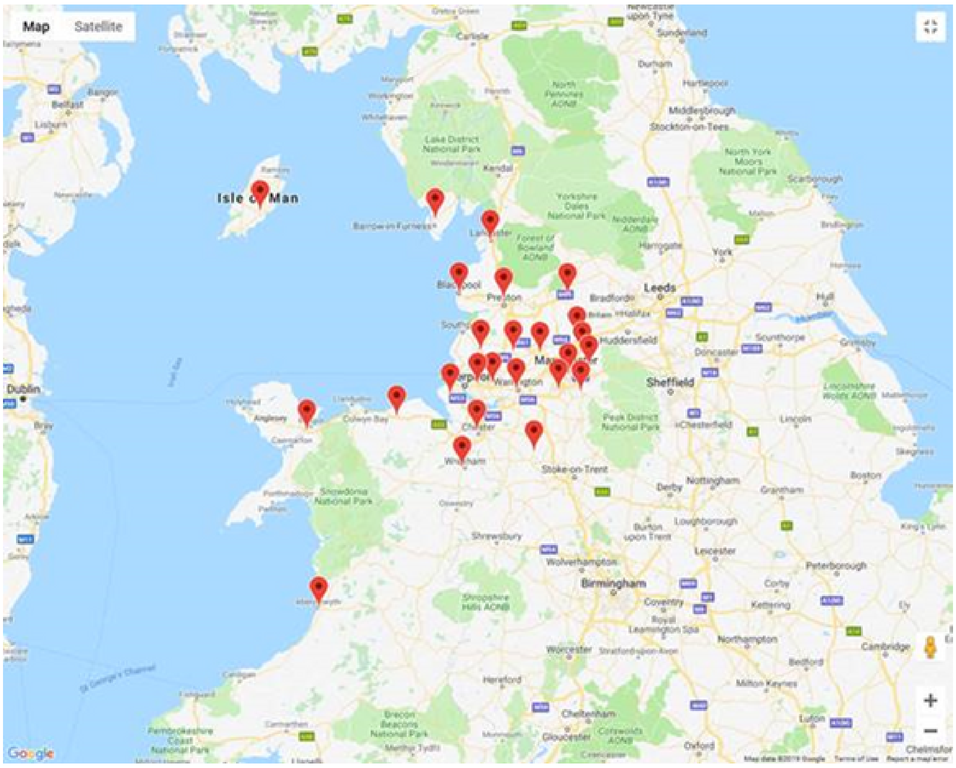
The North West, North Wales and Isle of Man Congenital Heart Disease Network is an ‘all-age’ (fetal to adult congenital) network responsible for monitoring the care provided to any patient with congenital heart disease. Hosted by Alder Hey Children’s Hospital and funded by Specialised Commissioning the network functions as an Operational Delivery Network (ODN).

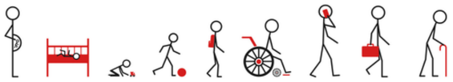
History & Geography

The North West, North Wales and Isle of Man Congenital Heart Disease (CHD) network has been in existence since 2012, formally becoming an ODN in September 2019.

The Network’s purpose is to bring together clinicians, nurses, allied health professionals, managers, commissioners and patients to improve the Congenital Heart Disease service within the region.

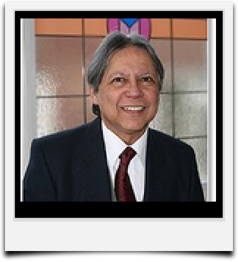
The Network covers a large geographical area including the North West region, North Wales and the Isle of Man, covering a population of approximately 7.5 million people. The North West has a high level of deprivation - 19.6% of conurbations in the region fall into the top 10% most deprived areas within England.





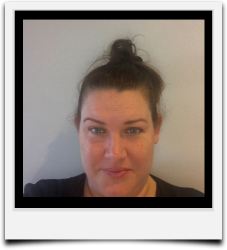
MEET THE TEAM

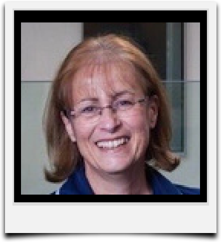

Gordon Gladman, Clinical Director


Nayyar Naqvi, Network Board Chair

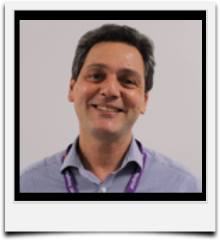

Dr Caroline B Jones
Consultant Paediatric Cardiologist

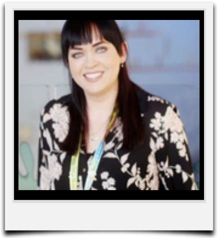

Dr Damien Cullington
Consultant Adult Cardiologist


Helen Sanderson
Network Manager

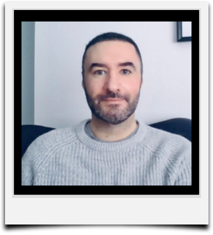

Linda Griffiths
Lead Nurse


Rob Johnson
Network Governance Lead

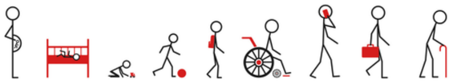

Vas Papaioannou
Network Governance Lead


Jemma Blake
Data Manager

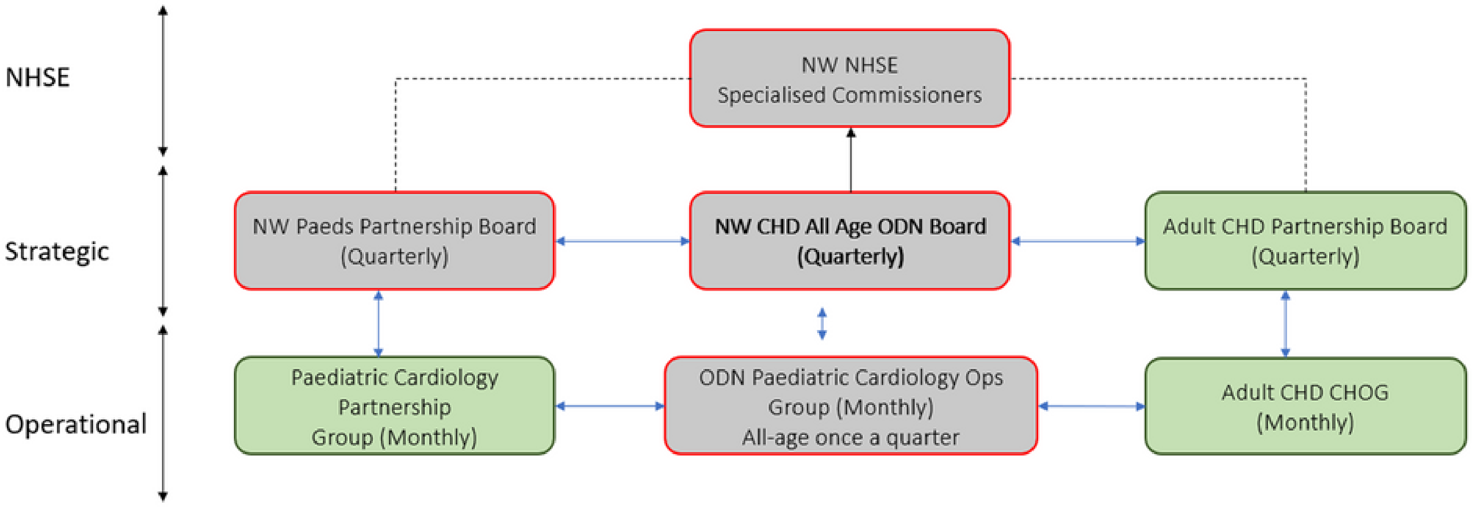

Jill Moran
Network Support Officer


Kenny Ward
Project Manager


Dan Short
Project Manager



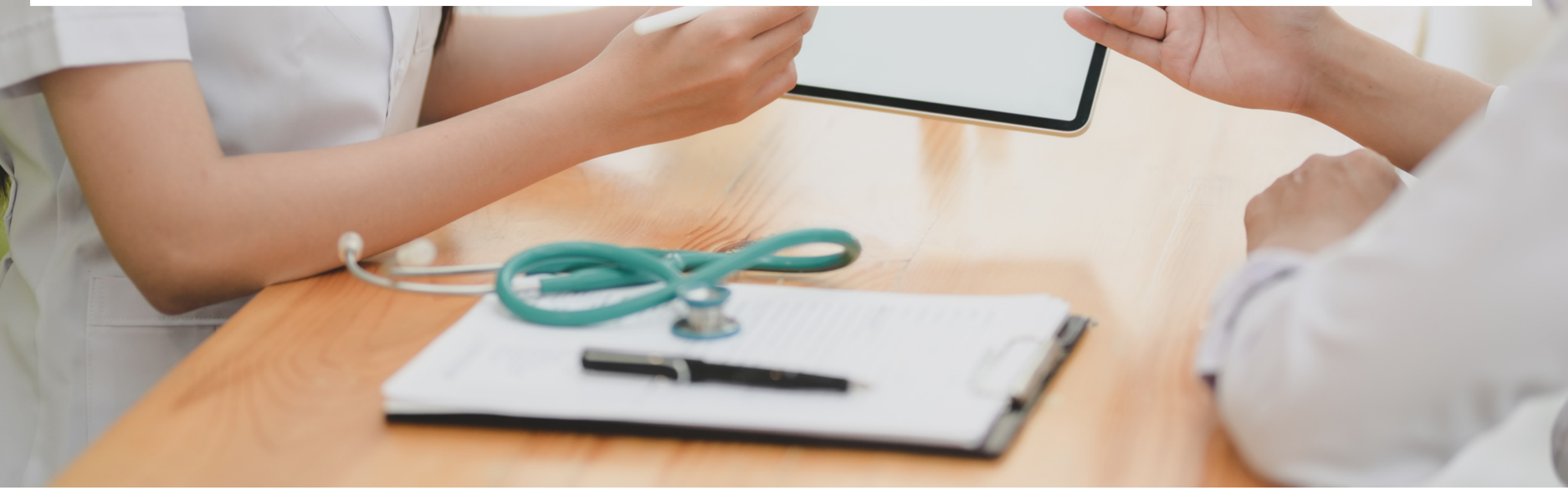
GOVERNANCE STRUCTURE

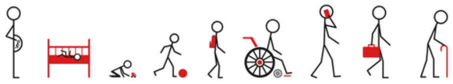


Task & Finish Groups; PPV group meet regularly and provide representation to above committees where mandated.

⚪ ODN Governance

🟢 Provider Governance





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OUR VISION

To support through collaboration, education and improvement, the delivery of world-class congenital heart disease services for patients and families in the North West of England, North Wales and the Isle of Man.

AIMS

To provide a high quality, fit for purpose capable network, demonstrating value & providing strategic direction

To provide assurance that 'national standards' are being met across the network, ensuring quality & safety and to work with providers where any 'gaps' in service provision are identified

To provide seamless care across the region, ensuring equity of access and egress to services in a timely manner, with the aim of providing high quality care as close to home as possible

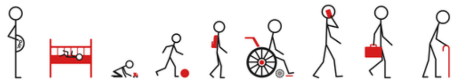
To develop digital systems that enables the sharing of clinical information between regional providers in a timely manner

To put the patient at the heart of all CHD services

To use digital solutions, informatics, outcome data and innovation as a tool for service improvement

To have a robust and clear clinical governance framework to support quality improvements in care that benefit patients regionally

Network to respond to unusual and unexpected events in a professional and logical manner to ensure the safety of patients and professionals



COVID-19 PANDEMIC

Covid-19 has had a monumental impact on patients' lives and provided massive capacity challenges for the NHS. As the pandemic continues, now 2 years later, the NHS continues to;

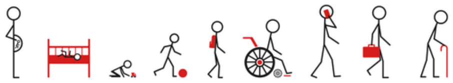
- Provide huge logistical operation that is the national vaccination programme.
- Continues to provide essential services to all that needs them,
- Manage operational challenges such as large backlogs, capacity and demand issues, staff absence & exhaustion
- Meet public expectations as much as possible
- Continue to tackle health inequalities
- Provide restoration and recovery for both services and staff

Covid-19 has presented the NHS & its staff with the most difficult challenges faced within a generation. Although there undoubtedly remain major challenges ahead, every colleague (clinical/non-clinical) within the Network responsible for providing care to families and patients, has risen to these challenges, supported each other and are to be congratulated for maintaining:

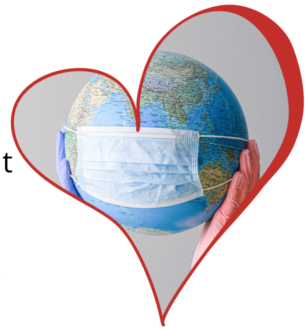
- a reduced but effectively safe outpatient service (paediatric and ACHD)
- continuing to provide 'time appropriate' cardiac surgical and catheter treatments for both paediatric cardiology and ACHD patients (no 'detrimental' cancellations of urgent/emergency cases identified)
- maintaining provision of antenatal diagnostic services (fetal cardiology) and delivering 'all-around seamless' obstetric/cardiology care to 'high risk' pregnant CHD patients
- supporting families/patients at a worrying time regarding concerns over the inevitable delays/difficulties in the provision of their 'routine' care
- for maintaining/staffing inpatient facilities throughout the region where required

Future Objectives relating to Pandemic

The network will continue to monitor the impact of Covid-19 on provision of care for patients with CHD, provide support where necessary and continue to be involved in developing 'action plans' to minimise the impact for patients wherever possible.



COVID-19 PANDEMIC (Cont/d)



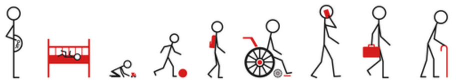
Maternity Services

- Maternity services have enabled birth partners of women with ACHD, to be present at the birth of their baby, throughout the pandemic
- Pregnant women with ACHD who would fall into the highly vulnerable category for shielding and prioritisation of vaccination were identified and notified
- A huge amount of work, across all maternity units in the Network, was undertaken to ensure pregnant women with ACHD received appropriate evidence based advice about vaccination in the face of rapidly changing national recommendations

As part of the national maternity strategy regional maternal medicine networks were being developed. The recently published Ockenden report has accelerated this work. There will be a single North West Maternal Medicine Network, which will provide care to pregnant women with underlying medical conditions, including ACHD. Maternity care will be provided close to home where appropriate, but in a tertiary Maternal Medicine Centre when necessary. Within the North West Maternal Medicine Network, there will be a Maternal Medicine Centre in Manchester, with developing Centres in Liverpool and Preston.

Network Achievements during Pandemic

- Organised and collected data form the level 1 & 2 service providers to monitor the impact of the pandemic on the CHD service& ability to provide care
- The network has been part of the regular national network teleconference, providing regional updates and learning from other regions in the country, providing assistance to ‘CHD partners’ in neighbouring regions where necessary/feasible
- The network has continued to listen and respond to concerns raised by the PPV group relating to impact of pandemic on families
- The network has continued to develop its website, ensuring valuable information (Covid and non-Covid) is provided to the public, as well as sharing regionally agreed protocols and pathways
- The network has facilitated sharing of information to the public relating to Covid-19, utilising (non-website) social media platforms
- The network initiated/hosted a regular, regional PECSIG meeting where Covid-19 information could be shared between providers around the region and support offered where necessary
- The network continued to provide education and training around CHD, incorporating Covid-19 information were appropriate



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PATIENT, PUBLIC VOICE REPRESENTATIVES

The network has a robust, mature and well-developed Patient and Public Voice (PPV) group. Established in earnest in 2020 the group has developed rapidly and become an essential part of the network.

ACHIEVEMENTS

Expanding the membership to incorporate wider age representation as well as a good geographical spread. The group includes patients, parents and a grandparent all with extensive experience of CHD

Spear-headed the development of a Paediatric Communication Audit that has led to a Paediatric Communication Questionnaire that is now live on the relevant websites

The group continually assess their role, referencing the National Standards, and are determined that the patient experience, for all age groups , will be the best it can be

It was discovered that a number of families had not received follow up appointment letters or letters updating them about the changes to the service caused by the Covid 19 Pandemic. The PPV group brought this to the attention of MFT/RMCH and had two meetings with management staff from the trust to highlight the difficulties parents were facing. As a result further communications were issued, supported on social media by the PPV group members reaching their networks

The Group has committed a considerable amount of time to their role in the Network. Meeting at least twice a month, as well as attending other meetings and spending many hours working on the projects mentioned below

It was decided by the group that a Chair/Facilitator was needed. Janet Rathburn volunteered to take on the role

Developing patient information leaflets to help patients make the most of their clinic appointment which will be published on the relevant websites

The PPV group have defined the need for, and parameters of patient events during Covid-19 using Facebook live and Zoom platforms

Provide a Patient Voice on all Network board meetings and a wide range of other meetings and task and finish groups

Developed an application process supported by a role description, volunteer agreement form and welcome pack

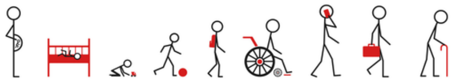
The PPV group escalate concerns from patients and families to the network and monitor the response

PPV reps have been instrumental in reviewing and updating the Network Website

2 members supported the Network Maturity Review

Work is ongoing on an Adult Communication Questionnaire

Support the development of the network database



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PATIENT, PUBLIC VOICE REPRESENTATIVES (Cont/d)

The PPV group highlighted concerns regarding:

- Waiting times and delayed appointments
- Difficulties with the PAS system
- Lack of Admin support

The Network assisted with implementing measures to help resolve/monitor these issues.

The group receives all the reports the Network produces and raises concerns they feel to be appropriate.

FUTURE WORK

- Continue to further develop the group and ensure that the skills of all the members are utilised
- To produce a PPV Work Plan
- Continue to provide a Patient Voice to the Board and in relevant Network meetings:

  - Develop Patient Information Days
  - Produce Patient Information leaflets
  - Working with the developing North West Children's Heart Partnership

Learning Disabilities

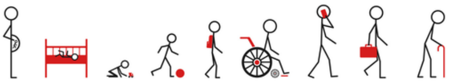
The network lead nurse (Linda Griffiths) highlighted her concerns that CHD patients with learning disabilities might not have adequate representation within the network or the PPV group. Therefore, she undertook to assess/improve this situation.

ACHIEVEMENTS

- Develop improved network contact with Mencap, Pathways Associates, Downs Heart Group, NHSE CYP and Autism lead.
- Establish a CHD LD 'focus group' - the first meeting of members was held on the 25th of September 2021 and was felt to be useful
- It was agreed regular 'virtual' meetings be organized/hosted by the network
- The minutes from these meetings have been shared with clinical teams so they are aware what is currently important to patients with LD

FUTURE WORK

- Potentially establish a network 'working/support group' specifically for CHD patients with Learning Disabilities.



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PATIENT, PUBLIC VOICE REPRESENTATIVES (Cont/d)

Communications Audit

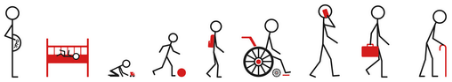
The PPV group raised concerns relating to poor communication between providers of paediatric cardiology and families. The network agreed to undertake a communication audit project. A ‘communication questionnaire’ was developed following a patient focus group and is to be sent to CHD patients and their parents who are either having or have received assessment/treatment for CHD. It is hoped the results will highlight where deficiencies in communication exist and how best to remedy this.

NETWORK ACHIEVEMENTS RELATING TO THIS AUDIT

- Audit registered with Alder Hey audit department (Dr Mike Bowes clinical lead).
- Focus groups held in October and November 2020
- Questionnaire agreed & finalised based on focus group work and agreed by PPV group
- Online questionnaire developed by Alder Hey audit department
- Alder Hey audit department have set up a link for the website to the questionnaire as well as a QR code for the communication audit flyer
- Flyer designed/ created
- Alder Hey information department asked to provide network with list of patients on the PTL to enable the communication audit to be sent
- Aim to keep audit open ended and receive quarterly report
- Questionnaire now live will get quarterly report, first one expected early 2022
- Link shared with RMCH, Psychologists, charities, PECSIGs and link nurses to ask them to advertise and encourage families to complete

ON-GOING WORK RELATING TO COMMUNICATION AUDIT

- Flyer needs printing and mailing out to patients
- Communication around the audit needs to continue
- Data needs to be analysed and fed back into the service and the PPV group



PATIENT, PUBLIC VOICE REPRESENTATIVES (Cont/d)

PREMS

Patient reported experience measures (PREMS) provide a means to capture what patients, parents and carers think about a service. A previous national CHD specific PREMS survey unfortunately was shelved. Clear communication and understanding the needs and thoughts of CHD patients remains an essential part of good quality care, recognized within the national standards. The Network has been active in assessing options as to how best to capture patient experiences across the region.

ACHIEVEMENTS

- PREMS option appraisal completed.
- Network PREMS Questionnaire to be 'all-age' and cover all levels of care
- Financing agreed by Senior Leaders Team
- To include transition and Learning Disability patients
- Would provide quarterly reports to the network
- Working with Lead specialist nurse from LHCH

FUTURE WORK

- Agree ACHD questions following focus group with PPV group and ACHD professionals.
- Agree contract with supplier
- Build the PREMs survey and go live
- Collect and report on data

AUDIT OF NATIONAL STANDARDS

Audit is an integral part of the NHS, clinical care and our CHD Network. Clinical audit is a method to ascertain if healthcare is being provided in line with standards and permits care providers and patients to assess if their service is doing well and identify where changes might be made to improve outcomes for patients.

Clinical audit is one of the key compliance tools at the Board's disposal and has an important role within the assurance framework.

In 2016 the findings of the New Congenital Heart Disease Review were published. The review made recommendations for a model of care, outlined expected standards and service specifications with the aim of earlier diagnosis and better information dissemination.

The CHD Network has the responsibility to audit and monitor the compliance of all levels of hospitals within the CHD service against these national standards and during 2021-22, the Network has developed an audit tool to assess how units are performing against these standards.

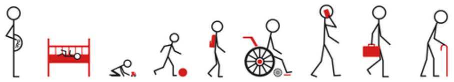
Conversations with Welsh Commissioners and the South West and South Wales CHD network resulted in co-operative working, whereby both the North West and South West CHD network agreed to produce a strategy/ process to audit the Welsh level 2 and 3 units against the NHS national standards. This audit will provide an overarching 'all of Wales' report for the Welsh commissioners (the final report is expected to be completed by Spring 2022).

ACHIEVEMENTS

- Agreement between the South-West and South Wales CHD Network, the North-West, North Wales and the Isle of Man CHD Network made and Welsh NHS Commissioners WHSCC to audit all unit against the national standards
- Strategy and documents designed and agreed
- Invitations and audit document sent to all units/ Health boards
- All audit meetings attended, and action plans developed where necessary
- Final report being written

FUTURE PLANS

- Agree final report and progress agreed action plans
- Tweak strategy documents based on Welsh audit experience for future use
- Agree strategy/timeline to audit every unit within the North West, North Wales and Isle of Man
- All units to have an agreed annual action plan available for review and to undergo a 5 yearly full audit review



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CLINICAL AUDIT 2022-23

FUTURE PLANS

- Develop a strategy for collating all network wide audits
- Develop a storage system where these audits can be held and be made available to all members of the CHD Network

The Network proposes to develop a prospective Network wide database of clinical audit with the objective to collate and organise all CHD audits into a single ‘library’ where any health professional can access them. The aim is that unrestricted access to clinical audit, should reduce duplication of service provision/monitoring and so improve patient care and the quality of CHD care across the network.

ICS FRAMEWORK & IMPLICATION FOR THE NETWORK

In 2021-22 the NHS Executive has outlined their vision for Integrated Care Systems (ICSs) and the changes that they will bring to established Networks. ICSs are partnerships that bring together Providers and Commissioners of NHS services across a geographical area with Local Authorities and other local partners to collectively plan Health and Care services to meet the needs of their population. The central aim of an ICS is to integrate care across different organisations and settings, joining up hospital and community-based services, physical and mental health, and health and social care. All parts of England are now covered by one of 42 ICSs.

ICSs are likely to produce major changes in how health and care services are planned, paid for and delivered. They are a key part of the future direction for the NHS as set out in the NHS Long Term Plan. It is hoped that by facilitating close integration of health and care services this will improve overall population health and reduce inequalities; encourage better productivity and sustainability of services and help the NHS to support social and economic development.

Despite being mandated by NHS England and NHS Improvement, ICSs (and before them Sustainability and Transformation Plans or STPs) have no basis in legislation and no formal powers or accountabilities. However, this looks set to change soon, with plans to put ICSs on a statutory footing from 2022.

Additional information around ICS's can be found using the following links:

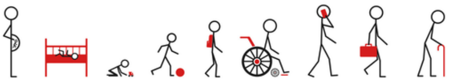
Integrated care systems explained:
The Kings Fund - kingsfund.org.uk

NHS England - What are integrated care systems?: england.nhs.uk

Report template - NHSI website - Integrating Care: england.nhs.uk

Report template - NHSI website - Design Framework: england.nhs.uk

NHS Long Term Plan:
The NHS Long Term Plan



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ICS FRAMEWORK & IMPLICATION FOR THE NETWORK (Cont/d)

Networks have and continue to prove their value in co-ordinating pathways of care, ensuring equitable access to healthcare and so reducing health inequalities, assuring and improving quality. Consequently, networks are anticipated to play a pivotal role in ICSs moving forward as this success is built upon.

The upcoming year will see Congenital heart Disease Networks continue to develop and prepare for the new ICS landscape. Work has started and will continue through 2022-23 to ensure networks are ready:

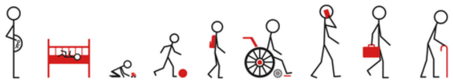
- Preparing accountability & reporting systems
- Aligning governance & quality systems
- Clarifying specifications
- Confirming funding arrangements
- Ensuring strong governance systems
- Preparing to take on additional responsibilities and deliver more effectively.
- Able to provide assurance around value for money and demonstrate the benefit of networks.

RELEVANT ACHIEVEMENTS

The North West, North Wales and Isle of Man Network is working locally and nationally to ensure that we are ready for the upcoming ICSs proposals. Working with Commissioners, Providers, and other Networks to ensure that we are prepared for the future changes and able to continue to develop and improve the quality of CHD care across our area and nationally.

FUTURE PLANS

The Network will continue to participate, develop and adapt to the emerging ICS frameworks to ensure the best possible care for its population.



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STRATEGIC DEVELOPMENTS

The Network has been involved in two strategic ventures (both on-going) during 2021-22. The ACHD Single Patient Treatment List (PTL) and the Paediatric Cardiology Partnership both aim to:

- improve patient care
- improve access and egress
- improve quality

ACHD SINGLE PTL PROJECT

Patients within ACHD services are currently managed through patient treatment lists (PTLs). Each provider has its own hospital-based patient administration system (PAS) for the management of these lists. Patient demographics are stored within the PAS systems and are used to manage clinic activity and capacity on a day-to-day basis. Importantly they are used clerically to manage parts of the patient pathway including monitoring of the Referral to Treatment (RTT) pathway. These systems struggle to monitor backlogs, audit DNA rates and at times, even identify all the patients for whom the provider is responsible.

It is therefore difficult to accurately record the overall number of ACHD patients being cared for within the Network. There are 3 different levels of hospitals within the network providing ACHD care and each hospital uses a different system.

PROGRESS/ACHIEVEMENTS TO DATE

- Agreement from all level 1 & 2 providers to enable a single PTL
- Agreement from the ACHD Partnership Board & Commissioners on developing a single PTL
- Single PTL a Regional Commissioners' priority objective for 2022-23
- Work on-going to assess the feasibility of incorporating the single ACHD PTL in the proposed network regional database
- Agreement that the 'single ACHD PTL' should sit within the ACHD level 1 centre

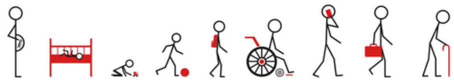
There is a recognized risk that patients might become lost to follow-up. The systems can also result in an inappropriate use of a limited specialist resources with on occasions, unnecessary duplication of appointments.

The ACHD Partnership Board therefore made the collective decision to move towards a single patient treatment list. This decision was supported by commissioners and the regional CHD Network. The aim of the project is to:

- Ensure patient safety and reduce clinical risk
- Provide High quality accurate data
- Reduce ACHD patient backlogs
- Permit effective and dynamic capacity and demand planning
- Facilitate a comprehensive equitable service provided across the region

FUTURE PLANS

- Undertake a scoping exercise, leading to a 'road-map' to formulate the development of the single PTL
- Discuss with involved parties whether the single PTL should be part of the proposed network database
- Undertake 'costing exercise' relating to the development of the single ACHD PTL
- Agree supplier and define contracts
- Agree and define contractual responsibilities around the single PTL
- Start work to build single PTL



STRATEGIC DEVELOPMENTS (Cont/d)

PAEDIATRIC CARDIOLOGY PARTNERSHIP GROUP (Single Service)

The network provides representation to the regional North West Paediatric Cardiology Partnership Group. The partnership is a shared initiative involving the two main providers of Paediatric cardiology within the region (Royal Manchester Children's Hospital and Royal Liverpool Children's Hospital/Alder Hey) with the aim of optimising co-operation between the two Trusts, the objective being to deliver equitable and outstanding child centred cardiology care across the North West.

The Partnership aims to:

- Improve patient experience through timely access to cardiology services within Alder Hey, RMCH and the North-West
- Develop a joint approach to cardiology services and specialist clinics at both sites
- Develop a joint approach to education, training and potentially a joint cardiology workforce
- Develop a clear common approach to Research and Innovation
- Optimise Paediatric cardiology referral and treatment pathways
- Develop a single service for Paediatric cardiology across both sites, which is resilient & capable of meeting patient-led demand
- Enhance/optimise capacity and access to diagnostic imaging, scans and interventional cardiology across both sites

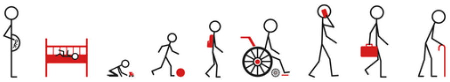
PROGRESS/ACHIEVEMENTS TO DATE

The Partnership is still in the early phase of development, but there is agreement to

- Appoint Clinical Leads and Project Support
- Agree vision and priorities outlined above
- Approve Terms of Reference and Governance model
- Undertake review of service provision across North-West & agree joint working

FUTURE PLANS

- Complete setting up the partnership
- Organisational agreements
- Operational review
- Operational set-up
- Single service 'go live'



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TRAINING & EDUCATION

Training and education remains an essential role for the network and despite Covid-19 we have attempted to provide high quality training and education to as many people as possible, aiming to ensure that we respond to the education and training needs of all members of the network.

ACHIEVEMENTS OVER LAST 12-18 MONTHS

- Continuing to work closely with colleagues at LJMU (Liverpool John Moore's University)
- Continuing to support the ACHD Masters Module. (8th November 2021)
- Supporting the development of the Paediatric CHD Masters Module, which has been ratified jointly by LJMU, Liverpool University and the Liverpool Centre for Cardiovascular Sciences (LCCS). This module will become part of a Masters in Cardiology that will be available for all health professionals, including clinicians, AHP and ANPs (expected to be live in 2022)
- Agreed to provide a network study day every 6 months and a clinical effectiveness meeting every 6 months
- The network has established a You-Tube channel on its website that is hosted by Alder Hey and will contain short educational videos
- Provide "an Introduction to ACHD" session every 8 weeks for interested nurses within the network

EDUCATIONAL MEETING

To facilitate the development of the network's education and training programme a CHD education working group has been established. This group first met in June 2021 and aims to bring together interested professionals to look at education provision for CHD across the region.

ACHIEVEMENTS

- Group membership presently includes clinicians, physiologists, nursing (all age), ANP and University staff.

NETWORK EDUCATIONAL EVENTS

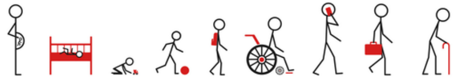
25th January 2021
Network Study Day
80 participants

2nd July 2021
ACHD Study Day
70 participants

15th September 2021
Paediatric CHD Study Day (link nurses)
50 participants

6th October 2021
Psychology/CHD Study Day
80 participants

19th November 2021
ACHD Study Day (link nurses(
50 participants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NURSING

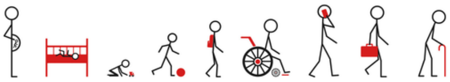
Following her appointment, Linda Griffiths, the network lead nurse has been leading on the nursing aspect of the network and has made notable progress in the last 12-18 months.

ACHIEVEMENTS

- Regular lead nurse meetings including representation from Liverpool Heart and Chest Hospital, Alder Hey Children's Hospital, Royal Manchester Children's Hospital & Manchester Royal Infirmary
- Paediatric Link nurse forum established and growing >40 nurses
- ACHD Link nurse forum established and growing >50 nurses
- Link nurse competencies and role description written, ratified and circulated
- Link nurse mentorship programme agreed and supported across the level 1 hospitals and the network
- Link Nurse teams/groups set up – providing educational resources/ videos/ teaching materials
- Nurse specialists recognized - involved in supporting link nurse programme, mentorship and teaching

FUTURE WORK

- Create a link nurse section on website
- Planning a small working group to look at developing resources for the link nurses



DATA KPIs/DASHBOARDS

2021-2022 has seen the network concentrate on collecting and monitoring high quality data and developing appropriate dashboards. Our aim has been to monitor performance and provide assurance during and beyond covid-19. In a very challenging year, our network data manager has managed to obtain, collate and analyse data which has allowed the network to provide assurances relating to the provision of clinical care to providers, commissioners and patient groups.

Jemma Blake
Cardiac & Clinical Information Data Manager
NW CHD Network

Achieved in 2021

- Building good working relationships with all Providers
- Weekly Operational Updates for the L1 Centre Providers
- Providing support to the development of the NW CHDN Database project
- National data from L1 providers to a national template
- National Surgical & Intervention data returns to the National Commissioning Tea at NHSE&I
- Producing dashboards for L1 & L2 Providers regional data
- Submitting Regional data returns to the Regional Commissioning Team at NHSE&I
- Circulate a cumulative Data Dashboard Regional Commissioner & to the Provider/Service Leads for continuous overview
- Design of robust data dashboard for L1 & L2 centres data for National & Regional CHD data returns
- Designed a dashboard, written & provided a descriptor to ensure regional & provider consistency to ensure data is comparable
- Monthly analysis of data
- Quarterly NW CHD Data meetings to present provider their data
- Providing quarterly data information to the NW CHD Network Board for the L1 & L2 Providers
- Supported both L1 centres in their most recent NICOR return
- Designed a dashboard for intervention & surgery that goes beyond the national request. Looking at cancellation rates, minimum/maximum length of wait. Dashboard went live in January 2022
- Monthly reporting to the NW CHDN Operational Group
- Regular reports to the PVV group
- Supporting the Network Database Project
- Supporting CHD in Primary Care project, providing data, access to data, investigation skills to the project lead nurse

Objectives for 2022

Support analysis of data for research & audits

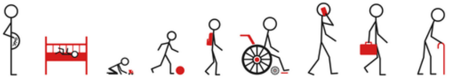
Support Transition waiting lists

Maintain high quality of data

Continued support to Providers

Support new Network Database implementation

Continued development of ACHD reporting



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CLINICAL GOVERNANCE

Clinical governance has remained a major focus for the network over the last year. The systems, SOP and methodology for standardising the network reporting of CHD incidents and mortality has been systematically worked through and finalised in late 2021. Two CHD Consultants (one ACHD and one Paediatric Cardiology) agreed to take network governance roles to support this work, along with a project manager.

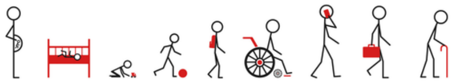
Dan Short
Project Manager
NW CHD Network

Achievements so far....

- Regular meetings with Leads, L1 Service & Clinical Leads
- Implementing cost effective processes for Network
- Implementing Microsoft products for Clinical Governance processes
- Creation of Task & Finish Group for governance leads
- Creation of paediatric & adult mortality review proforma
- Creation of incident submission portal
- Working with clinical leads from L1 centres
- Continuous user & scenario testing
- Creation of SOP for workstreams & ensuring ratification via NW CHDN Board
- Regular Clinical Governance Group meetings (due to staff sickness on hold)

Next Steps....

- Pick up & launch clinical governance workstream
- Progress governance meetings, research development, Board & Clinical Effectiveness Documentation
- Support colleagues Network projects and data work
- Continue work with Clinical Leads to progress governance processes



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ALL AGE CHD NETWORK DATABASE PROJECT

North West, Isle of Man & Wales

The CHD Standards and specifications document outlines the fact that CHD is a lifelong condition and most patients will require access to specialist care, including monitoring by appropriately trained specialists, throughout their lifetime. The care and monitoring of patients can encompass the full life course from neonatal diagnosis into paediatric and adult services meaning that the a full digital database project solution to track, record and report from individual sites to a national level is incredibly important to implement.

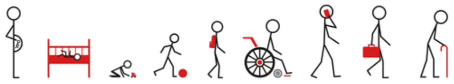
Kenny Ward
Project Manager
NW CHD Network

Achievements so far....

- Senior Leadership Group creation
- Operational Group creation
- Project governance and documentation created
- Risks defined and managed
- MoSCoW requirements chosen and defined
- Database baseline requirements defined
- Current L1-L3 Data culture document created
- Repository database review and recommendation made
- Initial costs gained - now inapplicable due to new single PTL scope
- External supplier discussions inititated

Next Steps....

- Funding for Single PTL incorporation – further discussions to define impact
- Define technical system link strategy and impact with sites
- Define and sign contract with supplier
- Redefine scope and timelines



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eLEARNING & EDUCATION PROJECT UK WIDE

Kenny Ward
Project Manager
NW CHD Network

In the summer of 2020 – BACCNA undertook a UK wide survey of nurse education that identified a gap in training and education for band 5 nurses regardless of whether they worked in a CHD specialist centre or not and all nurses working in non-CHD centres regardless of their grade. It also correlated with increased anxiety when looking after patients with CHD. It has been assumed that this is probably replicated across all disciplines and not just nursing – although this wasn't studied specifically. This work was presented at the National CHD Network meeting on 14th June 2021. There was agreement at that meeting that a project solution to bridge this gap was undertaken. The solution was found to be the creation of three UK wide introductory level eLearning modules - CHD overview, CHD Neonatal and CHD Adults.

Achievements so far....

Project funding secured and agreed

All project documentation including risk defined & monitored

Endorsement from HEE (health education England) and key contacts made

Full peer review undertaken with chosen UK team members

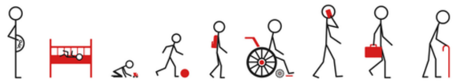
Three full first content drafts completed for all three modules

Creation on three key stakeholder groups

Working with external adult and paediatric charities to endorse content

Next Steps....

- Incorporate HEE advice and work with developers to finalise modules for online content
- Look at ways of expanding into a new project, looking at a different training focus area within CHD and how this might roll out with a larger scope
- Develop further with HEE a communications and engagement plan



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COMMUNICATIONS & ENGAGEMENT

As outlined previously, communication is essential to ensuring that the network achieves its goals, not only in the eyes of the network staff but also in the eyes of patients, parents, clinicians, nurses, and all professionals involved in the care of CHD patients.

WEBSITE

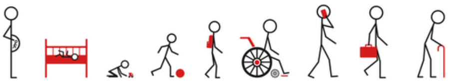
- A new site map for the network has been developed in the background of the current site.
- Website 'Fetus with CHD pathway' has been written, ratified and is now live
- Website 'Paediatric patient with CHD' pathway has been written and is in draft format on the website
- Website Teenagers/ young people pathway has been written and is in draft format on website
- Teenagers and young people E-brochure has been written, agreed, produced and finalised.
- Education section on website now live with links to presentations available
- Network documents are available and accessible on website
- Clinical guidelines and forms that have been ratified are accessible on website
- Board documents available on website
- Patient information leaflets available on website
- Network contact form live on website

FUTURE WORK

- Website ACHD information needs finalising and building
- Once Paediatric and Teenager/Young persons' pathways have been built and are live, a new homepage will be created, and we will convert to new site map
- Develop a Link nurse section

OTHER ACHIEVEMENTS

- Network newsletters have been produced every 6 months and have received excellent feedback.
- The Network Twitter page is live and regularly utilised. @NwchdH



COMMUNICATIONS & ENGAGEMENT (Cont/d)

National CHD Network of Networks

For the last 2 years the network has been part of a national network of CHD networks Covid-19 response forum. This group has met virtually weekly to monthly depending on need and the intensity of the pandemic. This forum has allowed sharing of information, trends to be predicted and understand the national picture for capacity and demand. This forum has yielded several achievements/ benefits to the network.

ACHIEVEMENTS

- Shared information on capacity and demand
- Good national understanding of pandemic on CHD service
- Shared information around PICU capacity
- Information shared around PIMS-TS infection rates

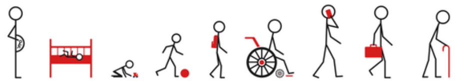
Prior to the forum becoming a Covid-19 response group, it was utilised to share learning and concerns around the CHD service and to facilitate shared learning opportunities. Each network would host a half or full day event every 6 months. On June 14th 2021, the North West, North Wales and Isle of Man CHD ODN hosted the latest meeting. This event was well attended and had good national engagement on the day.

Digital Working

Covid-19 has been a fundamentally negative event in history, but it has brought some improvements, one of which is digital working. The network, along with the rest of the NHS had to adapt rapidly. Virtual working, Microsoft Teams meetings, Zoom training & education events were all implemented quickly and successfully. An advantage of virtual working is that it has enabled more people to be reached and included in the network and the improvement of CHD services. As covid-19 abates the network will continue to use virtual platforms in combination with face-to-face meetings to reach and engage as many people as possible.

Zoom License

Zoom is one of the platforms the network has utilised to improve engagement across the area. A zoom license was purchased by the network during 2021 to support patient information days as well as training and education events where MS Teams could not accessed.



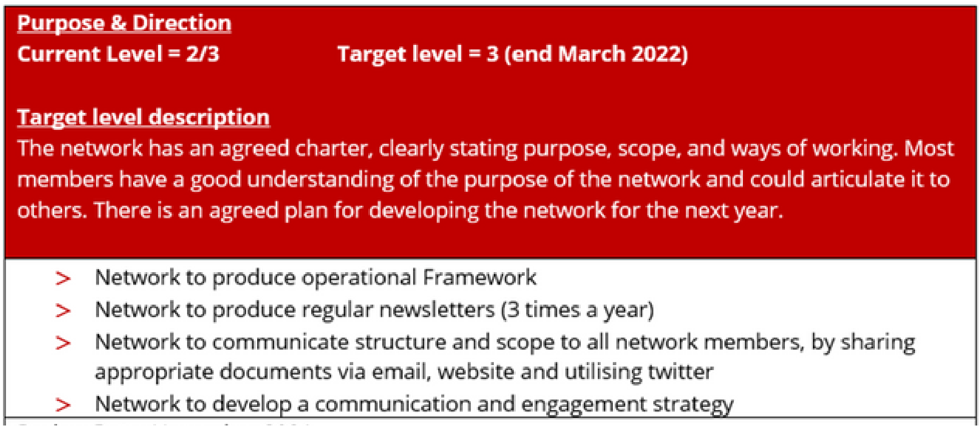
NETWORK MATURITY

The Network undertook a maturity review against a national maturity matrix in May 2021. The review consisted of a small group of network staff, commissioners, PPV reps and host organisation representative measuring the network against 8 well defined elements.

Once the network had assessed itself against each element, the group identified the top 2 elements it would like to concentrate on up to the end of March 2022 and the score we would like to achieve by the end of that time. The next two priority elements were then determined for the end of March 2023 and the score the network would like to achieve by the end of that time. A summary of these four main priorities are detailed below , along with the actions the network is currently undertaking or planning to initiate in order to improve our maturity score.

The network will review its maturity with regards to these priorities on an annual basis, at the beginning of each financial year with a mid-year update.

Priority 1

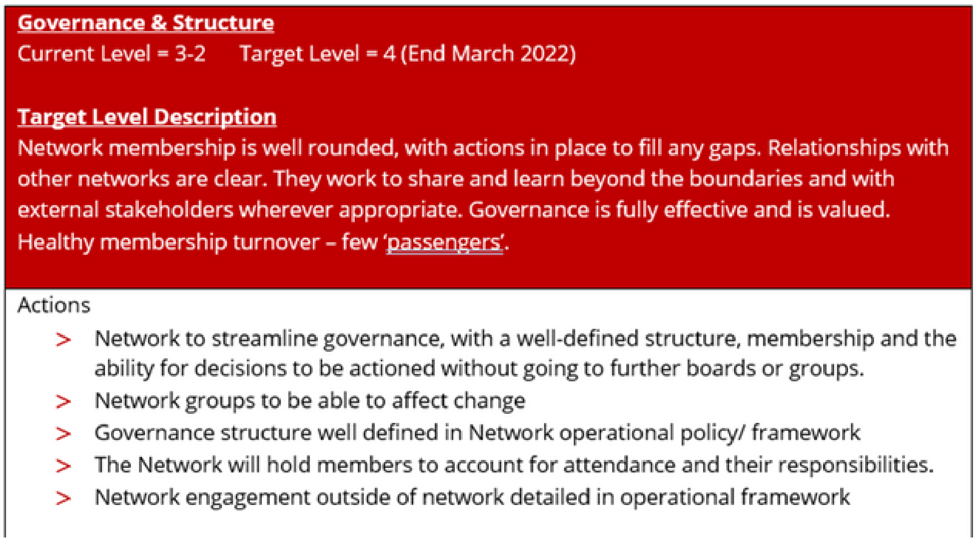


Purpose & Direction
Current Level = 2/3 **Target level = 3 (end March 2022)**

Target level description
The network has an agreed charter, clearly stating purpose, scope, and ways of working. Most members have a good understanding of the purpose of the network and could articulate it to others. There is an agreed plan for developing the network for the next year.

- Network to produce operational Framework
- Network to produce regular newsletters (3 times a year)
- Network to communicate structure and scope to all network members, by sharing appropriate documents via email, website and utilising twitter
- Network to develop a communication and engagement strategy

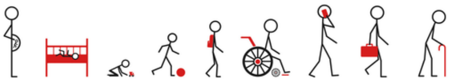
Priority 2



Governance & Structure
Current Level = 3-2 Target Level = 4 (End March 2022)

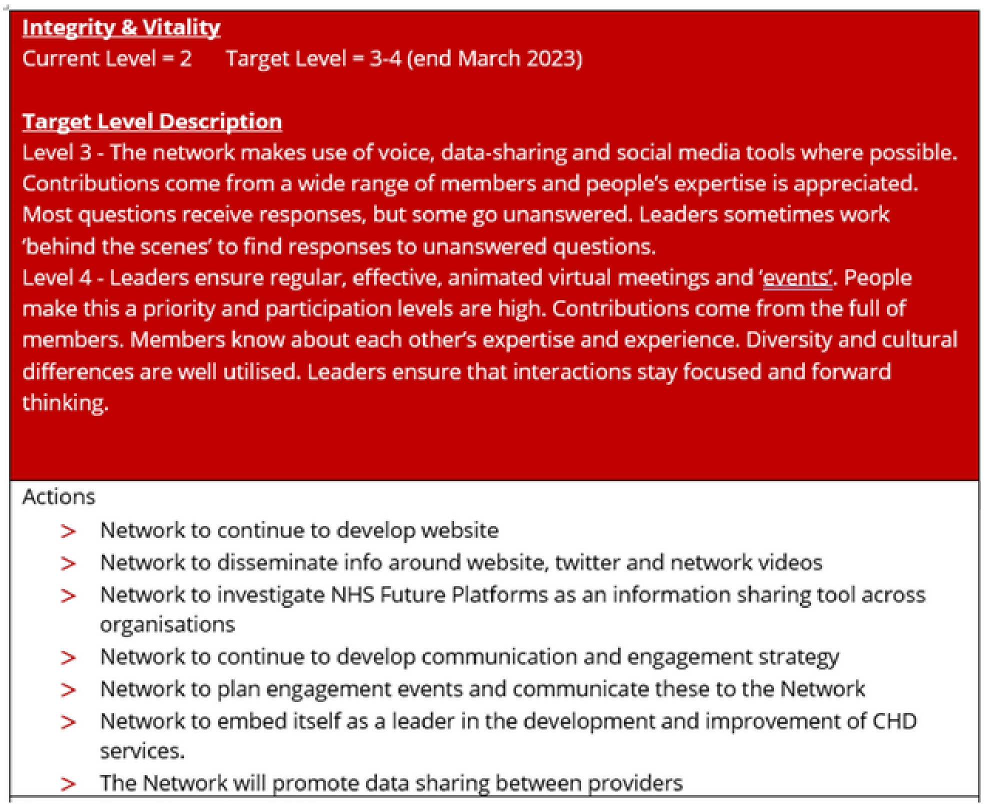
Target Level Description
Network membership is well rounded, with actions in place to fill any gaps. Relationships with other networks are clear. They work to share and learn beyond the boundaries and with external stakeholders wherever appropriate. Governance is fully effective and is valued. Healthy membership turnover – few 'passengers'.

Actions
- Network to streamline governance, with a well-defined structure, membership and the ability for decisions to be actioned without going to further boards or groups.
- Network groups to be able to affect change
- Governance structure well defined in Network operational policy/ framework
- The Network will hold members to account for attendance and their responsibilities.
- Network engagement outside of network detailed in operational framework



NETWORK MATURITY

Priority 3



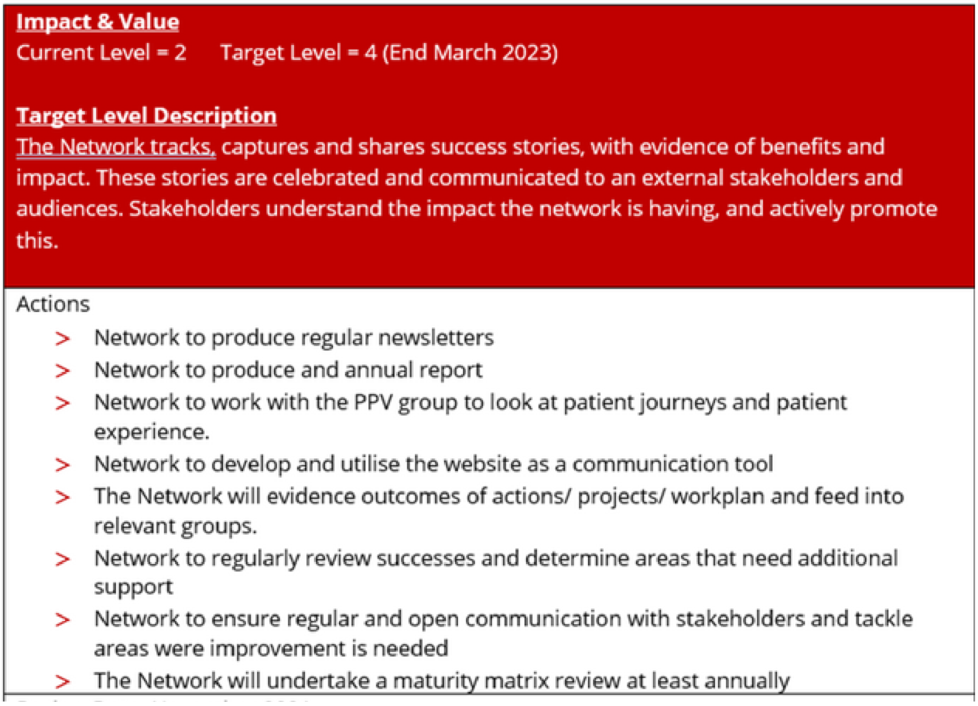
Integrity & Vitality
Current Level = 2 Target Level = 3-4 (end March 2023)

Target Level Description
Level 3 - The network makes use of voice, data-sharing and social media tools where possible. Contributions come from a wide range of members and people's expertise is appreciated. Most questions receive responses, but some go unanswered. Leaders sometimes work 'behind the scenes' to find responses to unanswered questions.
Level 4 - Leaders ensure regular, effective, animated virtual meetings and 'events'. People make this a priority and participation levels are high. Contributions come from the full of members. Members know about each other's expertise and experience. Diversity and cultural differences are well utilised. Leaders ensure that interactions stay focused and forward thinking.

Actions

- Network to continue to develop website
- Network to disseminate info around website, twitter and network videos
- Network to investigate NHS Future Platforms as an information sharing tool across organisations
- Network to continue to develop communication and engagement strategy
- Network to plan engagement events and communicate these to the Network
- Network to embed itself as a leader in the development and improvement of CHD services.
- The Network will promote data sharing between providers

Priority 4

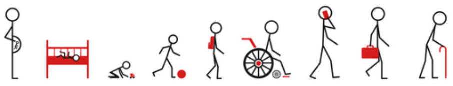


Impact & Value
Current Level = 2 Target Level = 4 (End March 2023)

Target Level Description
The Network tracks, captures and shares success stories, with evidence of benefits and impact. These stories are celebrated and communicated to an external stakeholders and audiences. Stakeholders understand the impact the network is having, and actively promote this.

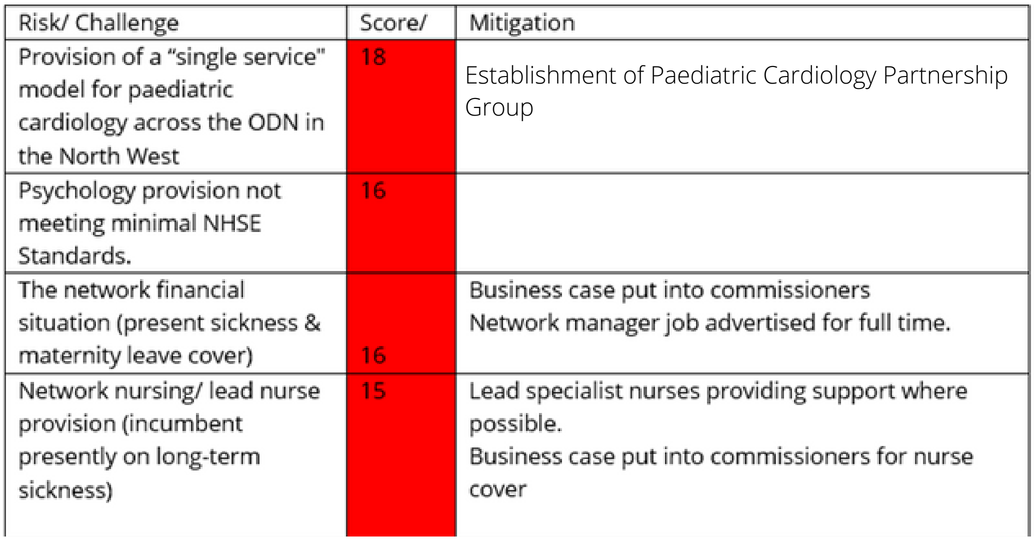
Actions

- Network to produce regular newsletters
- Network to produce and annual report
- Network to work with the PPV group to look at patient journeys and patient experience.
- Network to develop and utilise the website as a communication tool
- The Network will evidence outcomes of actions/ projects/ workplan and feed into relevant groups.
- Network to regularly review successes and determine areas that need additional support
- Network to ensure regular and open communication with stakeholders and tackle areas were improvement is needed
- The Network will undertake a maturity matrix review at least annually



NETWORK RISKS & CHALLENGES

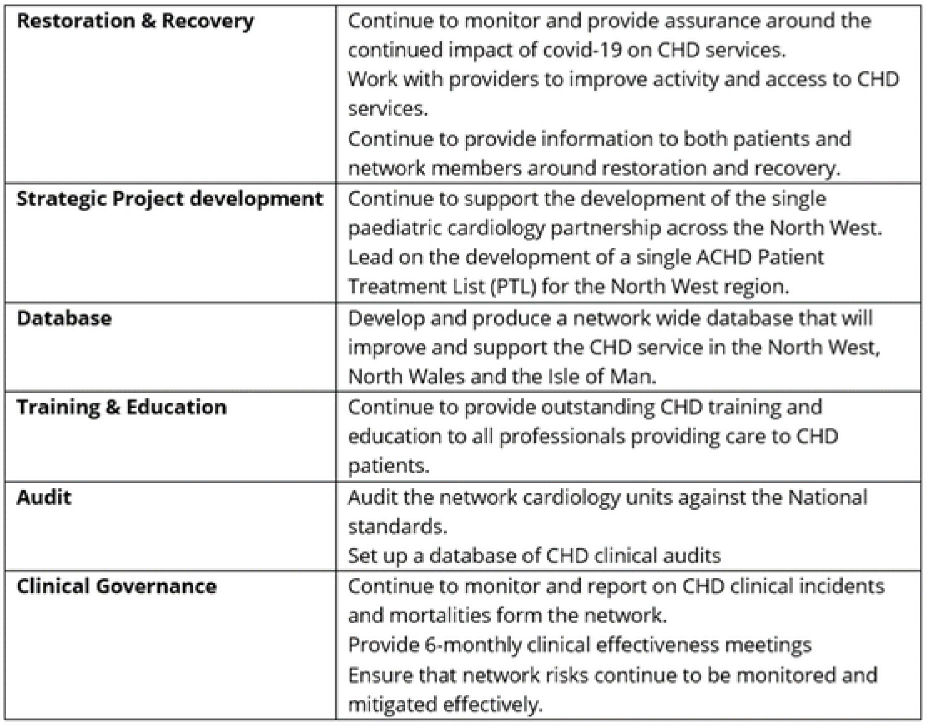
In 2021 the Network wrote, agreed and ratified our risk procedure. This process included the migration of the Network risk register onto the Ulysses system used by our host provider, Alder Hey Children's Hospital (though Network risks obviously remain independent of the host Children's Hospital own risks). All network risks are updated monthly with the overall risk register shared with the network board on a quarterly basis (any risk scoring >12 is individually discussed at the board meeting). At the end of 2021-22 the following are the highest risks on the network risk register.



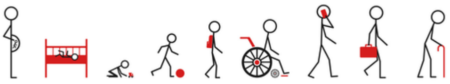
Risk/ Challenge	Score/	Mitigation
Provision of a "single service" model for paediatric cardiology across the ODN in the North West	18	Establishment of Paediatric Cardiology Partnership Group
Psychology provision not meeting minimal NHSE Standards.	16	
The network financial situation (present sickness & maternity leave cover)	16	Business case put into commissioners Network manager job advertised for full time.
Network nursing/ lead nurse provision (incumbent presently on long-term sickness)	15	Lead specialist nurses providing support where possible. Business case put into commissioners for nurse cover

OUR FUTURE PLANS 2022-23

The predicted work plan is included in the appendices; however, the top priorities are summarised below.



Restoration & Recovery	Continue to monitor and provide assurance around the continued impact of covid-19 on CHD services. Work with providers to improve activity and access to CHD services. Continue to provide information to both patients and network members around restoration and recovery.
Strategic Project development	Continue to support the development of the single paediatric cardiology partnership across the North West. Lead on the development of a single ACHD Patient Treatment List (PTL) for the North West region.
Database	Develop and produce a network wide database that will improve and support the CHD service in the North West, North Wales and the Isle of Man.
Training & Education	Continue to provide outstanding CHD training and education to all professionals providing care to CHD patients.
Audit	Audit the network cardiology units against the National standards. Set up a database of CHD clinical audits
Clinical Governance	Continue to monitor and report on CHD clinical incidents and mortalities form the network. Provide 6-monthly clinical effectiveness meetings Ensure that network risks continue to be monitored and mitigated effectively.

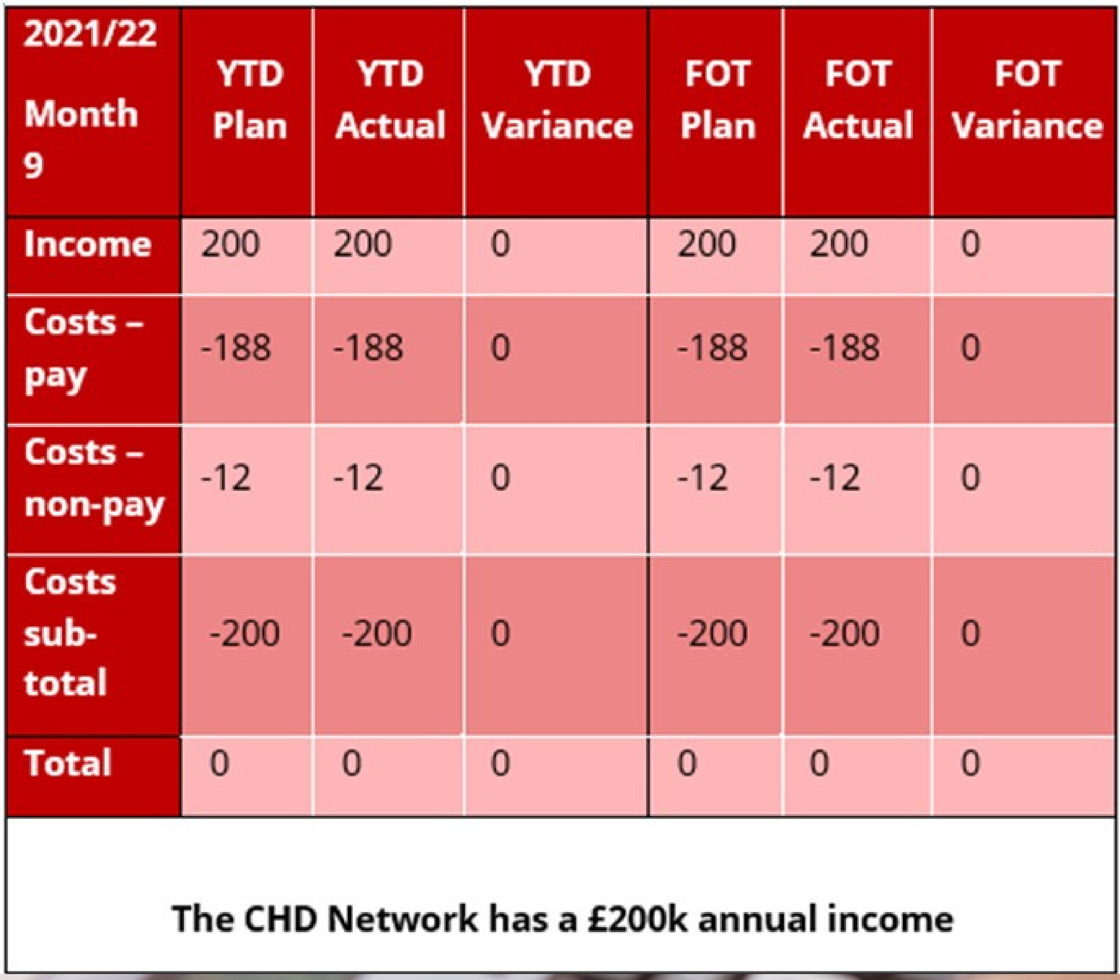


FINANCE

The North West, North Wales and the Isle of man CHD Network is funded by NHS England and has an annual budget of £200,000.

The End of Year financial statement is outlined below, the network utilised all of its annual funding this financial year.

Q4 (2021-22)



2021/22 Month 9	YTD Plan	YTD Actual	YTD Variance	FOT Plan	FOT Actual	FOT Variance
Income	200	200	0	200	200	0
Costs – pay	-188	-188	0	-188	-188	0
Costs – non-pay	-12	-12	0	-12	-12	0
Costs sub-total	-200	-200	0	-200	-200	0
Total	0	0	0	0	0	0

The CHD Network has a £200k annual income

CONTACT US

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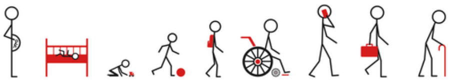
@NwchdN



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